

Transition among Children with Special Health Care Needs

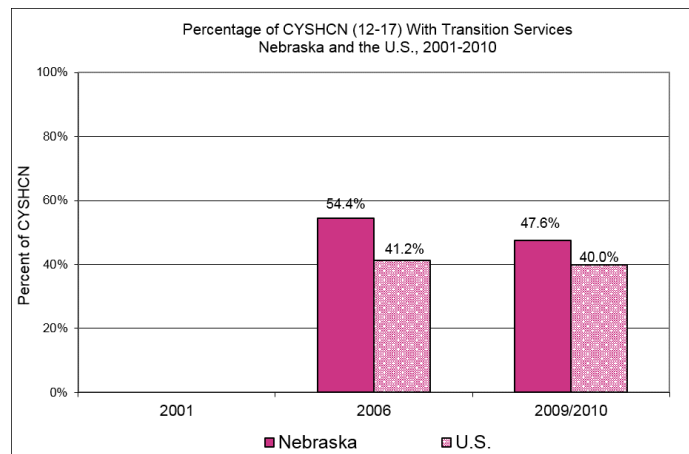
Transition services are defined as a set of activities for a child or youth with a special health care need (CYSHCN) or disability between the ages of 16 to 21 that: (A) is designed to be a results-oriented process focused on improving the academic and functional achievement of the child to facilitate movement from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation; (B) is based on the individual child's needs, taking into account the child's strengths, preferences, and interests; and (C) includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, when appropriate, acquisition of daily living skills and functional vocational evaluation.¹

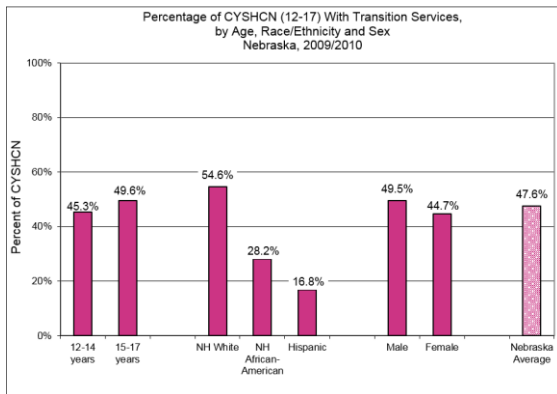
The percentage of youth, age 12 to 17, with special health care needs who receive the necessary services and supports to transition successfully to adult health care, work, and independence is 48% (see Figure). While this is higher than the national average; 52% of Nebraska student's transition needs are not being met.²

For youth with special health care needs transitioning into adulthood, having a clear path to post-secondary education, employment, health care, and independence with proper supports in place is critical to ensure success. Families of CYSHCN need information and support to make educated decisions to properly transition out of the educational system into the adult community based services and supports. Students with special health care needs can be successful and productive citizens if, when exiting high school, they have the proper services and supports in place. However, the future is grim for students with minimal family support or guidance to assist them in advocating for the necessary services for which they are eligible *before* they reach the age of transition (18 to 21). Certain pieces need to be in place to adequately meet the needs of these students transitioning into secondary education, vocational training programs, competitive employment, and/or independent community living; otherwise the problem will continue to increase.

Criterion #1: The Problem is Severe or Increasing Worse than the Benchmark

According to the National Survey for Children and Youth with Special Healthcare Needs (2009-2010), the percent of CYSHCN who receive the services necessary to make appropriate transitions to adult health care, work, and independence is lower than the previous survey conducted in 2006. In 2006, the percent of successful transitions was 54% and the most recent survey shows a decrease to 48%. This decrease demonstrates the need for focused intervention.





Additionally, supporting data shows that lack of awareness is a huge barrier to obtaining adequate transition services. It's a case of families not asking or advocating for specific services, because they are unaware of the available options. A study of the Community Supports Program (CSP) in Nebraska³ found the largest barrier (34%) to utilization of the program was families not understanding the program and professionals not being able to accurately explain it to families. Essentially, CSP is set up to provide individuals with community-based services and supports to assist them with daily living, work, and community participation. Other barriers to program utilization were rates established for providers and individual budget amounts set too low. This is also the case with other programs available to individuals with CYSHCN.

Criterion #2 – Disparities Exist Related to Health Outcomes

CYSHCN reflect the overall racial, economic and geographic demographics of the larger population of children and youth in Nebraska. However, research indicates that students with disabilities lag behind students without disabilities in terms of postsecondary academic preparedness. They are significantly less likely to even start postsecondary education than their peers without disabilities (27% of students with disabilities transition to postsecondary education compared to 68% of their peers without disabilities).⁴ It is also worth noting

that substantial data show that special education programs merely “feed” our prison systems when there is not enough support provided to youth with disabilities.⁵ As Nebraska looks to reform its current Corrections System and continues to improve its Juvenile Justice systems, it is important to consider research on “the school to prison pipeline.” Researchers have found that over 40% of youth with disabilities reside in juvenile justice facilities compared to 12% of the students in traditional educational settings.⁶

Disparities exist within the service systems primarily due to lengthy waitlists. According to Nebraska’s Division of Developmental Disabilities, there are 1,807 individuals with intellectual/developmental disabilities on a waitlist for comprehensive services (i.e., residential and vocational day services). Gaps in eligibility criteria make it especially difficult for individuals with co-occurring disorders (i.e., suffering from a combination of 2 or more mental, developmental, and/or intellectual disabilities) to obtain adequate services. Often times they are shuffled between service systems, because there is not a one size fits all program providing appropriate services to habilitate individuals with co-occurring disorders.

Even with these disparities, it’s important to note an individual must complete their course of study from a Nebraska High School and be found eligible for Developmental Disability Services in order to receive transition day services. Residential services are not considered an entitled service. This is important to remember, because even though parent’s feel as though their child needs to live outside their home, it doesn’t necessarily mean that they will receive those services through the state at the time requested. An entitlement program can be defined as: a government program which typically provides someone with a personal financial benefit if they meet eligibility conditions (e.g., Social Security, Medicaid, Medicare, and unemployment compensation). Someone may be eligible for developmental disability services; however, they

will likely have to wait until funding becomes available.

Healthy People 2020 Comparisons

According to HealthyPeople.gov, public health efforts, from the individual to the national level, can affect the health and well-being of people with disabilities. These efforts must respond to known determinants of disability and health.

There are many social and physical factors that influence the health of people with disabilities. The following 3 areas for public health action have been identified, using the International Classification of Functioning, Disability, and Health (ICF) and the 3 World Health Organization (WHO) principles of action for addressing health determinants.⁷

1. Improve the conditions of daily life by:
 - Encouraging communities to be accessible so all can live in, move through, and interact with their environment.
 - Encouraging community living.
 - Removing barriers in the environment using both physical universal design concepts and operational policy shifts
2. Address the inequitable distribution of resources among people with disabilities and those without disabilities by increasing:
 - Appropriate health care for people with disabilities
 - Education and work opportunities
 - Social participation
 - Access to needed technologies and assistive supports
3. Expand the knowledge base and raise awareness about determinants of health for people with disabilities by increasing:
 - The inclusion of people with disabilities in public health data collection efforts across the lifespan
 - The inclusion of people with disabilities in health promotion activities

The expansion of disability and health training opportunities for public health and health care professionals

All three of these areas not only address health conditions for those with disabilities, but they also speak to transition services for CYSHCN. When CYSHCN do not receive well-timed interventions and services, struggle with interacting with their environment as a result of barriers, and are unable to participate in everyday life activities they continue to experience health disparities, compared to the general population. (HealthyPeople.gov)

The largest set of U.S. health data for people with disabilities, DATA2010, measures health at the population level, and current data reveals specific health disparities for people with disabilities. Compared with people without disabilities, people with disabilities are more likely to experience difficulties or delays in getting the health care they need, experience symptoms of psychological distress, receive less social-emotional support, and have lower employment rates. (HealthyPeople.gov)

Criterion #3 – Strategies Exist to address the Problem/An Effective Intervention is Available

Much work has been done through the Nebraska Department of Education and with the establishment of Medical Home trainings with Pediatric practices to address issues with transition for CYSHCN age 16 to 21. The “medical home” concept is one of six core outcomes for systems of care reported as performance measures by all state Title V programs and reflected in the Nation’s Healthy People 2010 Objectives.⁸ School programs begin to implement transition plans within each youth’s IEP starting at age 16 through 21. By law,

at age 16 the school must have a written transition services statement in the youth's IEP.⁹ Many schools begin discussing transition earlier than 16 and include daily living skills building programs in IEPs by the time the youth reaches middle school. Transition plans provide information about adult services based on the student's wants and needs, building on strengths and interests of the student. These have actively been a part of IEPs for many years and yet the survey indicates students are less prepared for the adult world than in previous years. Ideally, a transition plan should be drafted by a collaboration of the student's parents/guardian, school district, potential adult service provider's, and other relevant entities.

Transition Advisory Committee: This committee was created in 1990 and is an advisory committee to the State of Nebraska Special Education Advisory Council (SEAC). The committee includes School Transition Specialists, parents, advocacy and agency representatives and meets three times per year. The committee addresses issues and concerns around the area of Transition and has developed various initiatives related to Transition.¹⁰ In recent years, the Nebraska Department of Education Transition Advisory Committee has developed and offered an annual Transition Conference for families and educators.

Transition Practitioners Committee: This committee was created to provide School Transition Specialists the opportunity to meet on a regular basis to discuss transition-related issues. They meet three times per year. The committee addresses issues and concerns around the area of Transition and has developed various initiatives related to Transition.¹¹

Project Search: Project Search is a nationally recognized model of employment for individuals with intellectual and developmental disabilities.¹²

The program requires real-life work experience for youth with disabilities as they transition from school to adult life. The program offers internships in multiple rotations where the youth can have many different work experiences and also receive job coaching and feedback. Nebraska has several Project SEARCH locations across the state. Project SEARCH is a partnership between Nebraska Vocational Rehabilitation, a business, area school systems, the Commission for the Blind and Visually Impaired, Assistive Technology Partnership, and Division of Developmental Disabilities. This one year school-to-work program is business led and takes place entirely in the workplace. The experience includes a combination of classroom instruction, career exploration, and hands-on training through worksite rotations.¹³ This link provides an overview of Project Search and its impact in one location in Nebraska: http://studio.omaha.com/?ndn.trackGroup=91341&ndn.siteSection=omahawh_nws_nonsty_dynamic&ndn.videoId=28197554&newheel=91341&siteSection=omahawh_nws_nonsty_dynamic&vid=28197554

Centers for Medicare and Medicaid Services Home and Community Based Services (HCBS): In January of 2014, the Centers for Medicare and Medicaid Services (CMS) issued their final rule on Home and Community Based Services (HCBS) within state Medicaid Programs relating to services being provided through Waiver programs. The rule reflects CMS' intent to ensure that individuals receiving services and supports through Medicaid's HCBS programs have full access to the benefits of community living and are able to receive services in the most integrated setting.¹⁴ The rule applies to all HCBS settings including non-residential, employment and training settings.¹⁵

This past summer the Workforce Innovation Opportunity Act passed with bi-partisan support

in both the Senate and House and was signed into law. Under the law, Congress reauthorized the Workforce Investment Act of 1998 and the Rehabilitation Act through 2020.¹⁶ While WIOA will help all workers have further access to education, job training, and support; it also has an emphasis on helping individuals with disabilities to find and maintain competitive, integrative employment with a specific focus on assisting youth with disabilities transition into adult life.

Having state specific information readily available to families and youth with special health care needs and disabilities can be as simple as providing a comprehensive web site of transitional resources and information. For example, the Cincinnati Children's Hospital hosts valuable information about the transition process on their website.¹⁷ This web site includes helpful information and opportunities to network with fellow parents on a variety of transitional topics, including transition planning, guardianship, estate and future planning, and vocational day programs. Cincinnati Children's Hospital also provides an on-site Transition Medicine team that focuses on partnering with teenagers and young adults with chronic health conditions or developmental disabilities to create a plan for healthcare transition as they get older.¹⁸

Criterion #4: Capacity and Support are Available to Address the Problem

When young adults with disabilities are preparing to make the transition from high school to work or postsecondary school, often times taking a person-centered planning¹⁹ approach to transition is forgotten in the process of securing new services. These much needed supports may include counseling regarding: secondary education, vocational day programs, employment training programs, Supplemental Security Income (SSI), Medicaid, Medicaid waiver services (funding),

housing, and transportation. In contrast to a young person's informal support network including family and school, adult service systems tend to be impersonal and formal in their methods of assessment. Service Coordinators, vocational rehabilitation counselors, and social workers often have large caseloads as well as a limited amount of time to know the individual needs and abilities of each person on their caseload. Parents are often left alone to try and figure out where to go and what to do, and the adult oriented supports they expect they will find in their community are just not there.²⁰

In Nebraska, students who have been deemed eligible for Developmental Disability Services can access day services at the age of 21. Students eligible for Developmental Disability Services remain in high school transition programs as other supports are not attainable during the three years between typical high school graduation and the end of transition services at the age 21. High school transition programs offer services geared towards building prevocational job skills and daily living skills to increase the likelihood of competitive employment and independent living post-graduation. Once the youth has reached the age of 21 and graduated, adult day services are provided by private providers who have contracted with the Nebraska Department of Health and Human Services Division of Developmental Disabilities. Services can be provided on a continuous or intermittent basis. The focus for intermittent services is employment. Young adults can use these services to seek employment or to have a job coach assist them in a job that has been secured (i.e., supported employment).

The federal Workforce Innovation Opportunity Act and recent regulations redefining home and community based services are two vehicles from which to build. In addition, much like the motto, "It takes a village to raise a child," it takes the

collaboration of systems (Families, Community agencies, Medicaid, Education, Department of Labor, etc.) to support a youth with disabilities to transition into adult services. We need to identify and implement strategies to share this information with families and guide them through the transition process.

LB320 proposed, by Senator Kate Bolz will continue the systemic goals of BIP including a “no wrong door/single point of entry” system and standardized assessments. The proposed bill would create Aging and Disability Resource Centers (ADRC). These resource centers would serve as an information clearinghouse for Nebraskans who are aging, disabled, and/or family members of aging and disabled Nebraskans. Information and services provided would include, but are not limited to: information and referrals, options counseling, streamlined eligibility determination for public programs, person-centered transition support when moving from one setting to another (such as when an individual moves from a hospital back into a home setting,) strategic partnerships with providers, and quality assurance. Other states with similar centers, such as the creation of the ADRC proposed in LB320, have found them to be cost effective and contribute positively to the key goals of promoting home and community based care and linking people to the right service at the right time.

Criterion #5: Severity of Consequences

In 2013-2014, the Nebraska Developmental Disability Council provided a grant to The Arc of Nebraska to conduct a study of the issue with input from regional workgroups of families and advocates gathering data, reviewing findings, and coming up with recommendations. The study was completed in May and four themes emerged from the analysis of the 451 surveys: challenges for families; service responsiveness; systems barriers, and unmet family needs. The primary concern was

the lack of information available to families about programs and services that could assist families who have children with disabilities.

Families noted that it is challenging when there are too many points of contact, most families are unsure where to begin, and there isn't a point person to guide them through the systems. Families also expressed concerns over service responsiveness, including lack of service consistency statewide, lack of accountability within systems (including educational and state services), lack of transition supports, and no outreach to families who are simply unaware of the available services.

Families noted system barriers in the Family Support Study, including waiting lists, burdensome paperwork to access services, misplaced paperwork within the system, unknowledgeable Service Coordinators, and access to medical and behavioral health professionals in the community.

The Arc of Nebraska's Family Support Study clearly identifies that families do not have the information or guidance necessary to help their children and youth transition successfully into adulthood.²¹

When youth are not prepared for self-care or self-directed health care it typically falls on families, communities, and the state to address the need for care. The community may not view this as a significant need when families carry the weight of the care for an adult child living within their home. Some families have not been able to access programs their adult children with a disability or special health care need are eligible for or have been denied access to such programs despite their continued efforts to appeal or reapply. Nebraska may not have appropriated the necessary funds to provide adequate services and supports to individuals with special health care needs. As stated earlier, the registry for Developmental Disabilities Home and Community Based Services

(HCBS) is case in point. Though funds have been increased in the past few years there is still an extensive waitlist of 1,807 for those 21 years of age and older to access community based residential and vocational day services through the HCBS Comprehensive Waiver. It's estimated that most families are waiting 5 years or more before being offered services.

Though this is not currently life threatening for CYSHCN, it can turn into a crisis situation in the blink of an eye. Dedicated families are caring for their children past the age of majority and into their adult years. There are families who are caring for their adult children throughout their elderly years. Case 1: 85 year old mother seeking services for her husband calls about a referral for services related to Alzheimer's care. It is discovered that she is also caring for her adult son with Down Syndrome, who is 65 years old. This situation could become tragic at any time. The mother was not knowledgeable about services that are currently available for her family. If the mother dies unexpectedly, her child is at risk for a placement in an Intermediate Care Facility (ICF), which is likely more restrictive than he needs, and is not community based. This is but one example reflecting the national crisis of aging caregivers caring for adult children with disabilities and special health care needs without knowledge of available services.

Individuals with mental health care needs often fall through the cracks. Gaps in eligibility criteria make it especially difficult for individuals with co-occurring disorders (i.e., suffering from a combination of 2 or more mental, developmental, and/or intellectual disabilities) to obtain adequate services. Often times they are shuffled between service systems, because there is not a one size fits all program providing appropriate services to habilitate these individuals. They don't qualify for developmental disability services, are not successful in their school's transition program or VR program (e.g., Project Search), and/or their parents haven't taken the necessary steps to obtain the much needed services they need to be successful in the future. Some individuals wind up

homeless, in the wrong type of placement, or worse - incarcerated. They have no one to advocate for their best interests and the idea of an individual living in the least restrictive setting is simply not possible.

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